Control Beliefs among People with Dementia: A Systematic Review

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Keywords

Dementia · Control beliefs · Self-efficacy · Coping · Psychosocial interventions

Abstract

Introduction: Dementia diseases are still incurable, and in order to assist in living well with the disease, researchers are increasing their attention to the value of control beliefs. Control beliefs are associated with coping and psychological well-being; however, knowledge on how they relate to well-being outcomes in people with dementia is limited. This review aimed to synthesize knowledge about control beliefs in this group to guide future interventions and research. **Method:** A systematic search of 6 databases (MEDLINE, CINAHL, PsychINFO, AgeLine, Embase, and the Cochrane Library) with broad search terms related to dementia, control, and coping was conducted. Studies that investigated people with a confirmed dementia diagnosis and that used a questionnaire to measure control beliefs quantitatively were included. **Results:** Eighteen studies were identified, examining self-efficacy, personal control/mastery, or locus of control. The studies varied in aim and design, with fair to good methodological quality. However, 10 studies included <50 par-

ticipants with dementia, leaving findings unreliable due to low power. Participants with dementia in the mild to moderate stages were included, with average age in the seventies. Except for one validation study, the control belief questionnaires had not been validated for people with dementia.

Conclusion: There is a lack of knowledge about control beliefs among people with dementia, due to few and low-powered studies. Although we cannot conclude regarding control beliefs, our findings support the feasibility of quantitative research on control beliefs among people with dementia and we recommend that they be included in this type of research.

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Introduction

No cure or treatment that can delay the progression of any dementia disorders are yet available, and due to an increase of older adults worldwide, the number of people with dementia will rise substantially in the years to come [1]. Over time, dementia leads to decreased ability to function cognitively, socially, and independently in everyday life. A growing interest regarding how to live and

cope with dementia is emerging [2]. Knowledge about how people cope with dementia has value for implementing interventions that target adaptive coping strategies for activities of daily living as well as behavioral and psychological symptoms due to the disease.

Control beliefs has been an area of research for more than half a century in social, personality, and clinical psychology. Experiencing a sense of control has repeatedly been shown to be beneficial when coping with a variety of health problems [3, 4]. Many control constructs have been developed [5], and the most prominent are locus of control, learned helplessness, mastery, and self-efficacy. Although defined as distinct constructs, each definition attempts to explain how a person views his/her abilities, effort, or expectations of realizing an outcome. Indeed, several constructs and definitions have been proposed as indicators of the same underlying personality construct [6].

Studies have shown control beliefs to be beneficial for coping [7, 8]. In health research, for example, perception of control has been found to affect one's ability to engage in positive health behaviors and adjust to a demanding situation [9]. In the 1970s, Langer and Rodin [10] demonstrated how a perception of control can positively impact upon well-being among nursing-home residents. In their intervention study, residents who were given more responsibilities in daily decision-making reported to be happier and appeared more active than that of a comparison group given the same activities but with a fixed time schedule. A positive difference was measurable even 18 months after the intervention. In addition, the study reported that the persons in the intervention group tended to live longer than those in the control group [11]. This study bridged the research on control among older people and control in health-related situations and helped shape subsequent gerontological research [8].

Control beliefs among older adults have been associated with the same tendencies as found among younger adults; less perceived control negatively affects well-being, and more perceived control leads to positive outcomes and overall successful aging [4, 8]. In addition, among healthy older people, more perceived control has been associated with greater use of effective strategies to improve memory and to maintain cognitive functioning [4, 7, 12]. According to Bandura [13], a person will invest more effort in a task when the outcome is believed to be attainable. As control beliefs are important to both mental well-being and cognition, they are likely important elements of psychosocial interventions for people with dementia. Knowledge about how con-

trol beliefs function among people with dementia could assist informal caregivers and health-care personnel in helping this group to cope with their progressive disease.

Research Aim

The aim of the present review was to synthesize knowledge on control beliefs among people with dementia by performing a systematic search of relevant quantitative research studies. By doing so, we wished to illuminate the present knowledge base and help guide future research on this topic.

Methods

Selection of Eligible Studies

A systematic, computerized search of quantitative research literature was conducted in the MEDLINE, CINAHL, PsychINFO, AgeLine, Embase, and the Cochrane Library databases. The search was conducted by a research librarian at 3 time points, April 2019, October 2019, and January 2021. The second and third searches were restricted to articles published after January 2019.

The search strategy included Medical Subject Headings (MeSH), keywords, and text words for the following constructs: *dementia*, *control*, and *cop-ing*. Perceived control can be viewed as an aspect of coping, and it is possible that some researchers have examined coping with the use of a control instrument; hence, *cop-ing* was included in order to increase the likelihood of incorporating all relevant research. Control beliefs have been defined in numerous ways [5]; thus, we performed a search with a variety of search terms in order to encompass relevant studies (see Appendix 1 for an overview of *dementia* search terms and Appendix 2 for *control* and *cop-ing* search terms).

The inclusion criteria in this review were research conducted by including persons with a confirmed dementia diagnosis, who had responded to a control belief instrument. Additionally, the research had to be original and peer-reviewed, have a quantitative design, and published after the year 2000. Reviews, protocols, conference abstracts, posters, or theoretical research were excluded as were articles in a language other than English. We also excluded articles that studied persons with dementia and mild cognitive impairment (MCI) as a single group, since we wished to have a clear focus on dementia.

The selection of relevant articles was performed in dyads to reduce the risk of oversights. One author was a member of every dyad throughout the selection process to ensure consistency. After an initial elimination of duplicates by EndNote, the selection procedure was performed as follows: First, all titles were divided into 3 parts and delegated at random to the 3 pairs (of the co-authors). Article titles that clearly did not meet the inclusion criteria were discarded. Disagreements within the dyads were resolved by consulting the other co-authors. The procedure was repeated when delegating and reading the abstracts, skimming the full articles, and, finally, when comprehensively reading the remaining articles. Last, a search for additional articles was conducted by examining the reference lists of all included articles.

Fig. 1. Overview of the review process.

Quality Assessment

A quality assessment of each article was performed using the critical appraisal tool developed by Hawker et al. [14]. This tool is applicable to all study designs and comprises 9 areas for review: Abstract and Title; Introduction and Aims; Method and Data; Sampling; Data Analysis; Ethics and Bias; Results; Transferability and Generalizability; and Implications and Usefulness. Each area is given a score between 1 and 4 based on a set of guiding criteria; the minimum sum score is 9 and the maximum is 36. A higher total score indicates better quality. Two authors scored the articles separately, and minor disagreements of one point were averaged. No articles were excluded based on their quality assessment. The appraisal tool by Hawker et al. [14] allows for an assessment that focuses on the quality of each research article regardless of study design, meaning that a cross-sectional study can receive a score equal to a randomized controlled trial.

Results

The 3 electronic searches yielded a total of 7,005 articles (final search performed in February 2021). EndNote was used to eliminate duplicates, resulting in 4,061 articles to be assessed for eligibility by the authors. After elimination first by a review of titles, then by abstracts followed by full-text readings, 16 articles remained. Two additional articles were found through examination of reference lists; thus, 18 articles were included in this review. Figure 1 shows the review process.

Methodological Quality of the Studies

As shown in Table 1, the studies had good methodological quality, with 12 studies receiving a score above

Table 1. Quality assessment of studies

Authors	Abstract and title	Introduction and aim	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability/generalizability	Implications/usefulness	Total (36)
Burgener and Twigg [19]	3	3.5	4	3	3.5	3	4	3.5	3	30.5
Burgener and Berger [21]	3	3.5	4	2.5	3.5	2.5	4	2.5	3	28.5
Burgener et al. [26]	3	3.5	4	2.5	4	2	4	2.5	3.5	29.0
Clare et al. [18]	4	3	3	4	4	3.5	4	4	4	33.5
Clare et al. [30]	3	4	3	3	4	2.5	4	3	4	30.5
Fankhauser et al. [25]	4	3	3.5	3	4	2.5	4	3	3.5	30.5
Fitzsimmons and Buettner [20]	2	2.5	2.5	2.5	2	1	3	2.5	2.5	20.5
Halse et al. [27]	4	3.5	3.5	3.5	4	4	4	3.5	3.5	33.5
Hindle et al. [17]	4	4	4	4	4	4	4	4	3.5	35.5
Lamont et al. [28]	3.5	4	4	4	4	2.5	3.5	3.5	4	33.0
Leroi et al. [31]	3.5	3.5	3.5	3	4	3	3.5	3	3.5	30.5
Logsdon et al. [24]	4	4	4	3	4	1	4	3	3	30.0
Quinn et al. [15]	4	4	4	4	3.5	3.5	4	3	4	34.0
Regan et al. [29]	3.5	3.5	3.5	3	4	3.5	4	3	3.5	31.5
Roberts and Silverio [23]	3	3.5	3	3	3.5	1.5	3.5	3	3	27.0
Schmitter-Edgecombe et al. [22]	2.5	2	3	3	2.5	1	2.5	3	2	21.5
Stockwell-Smith et al. [16]	3.5	3.5	3.5	3	4	2.5	4	3.5	3.5	31.0
Werheid et al. [32]	3	3.5	3	3	2	3.5	3	2.5	3.5	27.0

Assessment done using the appraisal tool by Hawker et al. [14]. 1, very poor; 2, poor; 3, fair; 4, good.

30, and no studies below 20. The studies were, in general, well-justified with good methodological considerations, clear results and discussion sections, and appropriate conclusions regarding implications and usefulness. However, only one study used a control belief questionnaire validated for people with dementia and 10 included <50 participants with dementia.

Study Designs of the Articles

Of the 18 included articles, 11 were intervention studies, of which 7 were pilot studies. The remaining 7 articles were observational studies, of which 2 focused on scale psychometrics. Only 2 intervention studies examined control belief as the primary outcome [15, 16] and another 2 as part of the secondary outcomes [17, 18]. The remaining intervention and observational studies included control beliefs as exploratory outcome measures or as dependent measures without further specifications [19–32].

Heterogeneity in terms of aim, study design, sample size and outcome measures deemed a non-statistical synthesis of the results appropriate. Table 2 shows an overview of the study details.

Study Settings

The participants' home was the research setting in 9 studies [16–19, 21, 23, 28, 30, 31], while 3 were performed

in recreational facilities, adult day care or senior centers, or in an assisted living facility [20, 24, 29]. One study was performed in a memory clinic [15], one allowed participants to choose between home or memory clinic [26], and another collected data at participants' home, day care, or memory clinic [27]. Finally, 3 studies did not specify research setting [22, 25, 32].

Participants

Although the age range of the participants with dementia varied from 52 to 96 years, mean age in all studies was in the 70s. Four studies had an age specification as part of their inclusion criteria, with a minimum age varying between 55 and 65 years [16, 17, 25, 27]. See Table 3 for an overview of demographics regarding participants with dementia. Demographics of participating caregivers or comparison groups are not presented in this review.

Dementia Diagnosis

All studies in this review included participants with a confirmed dementia diagnosis; however, only 10 reported which diagnostic criteria had been used [15–18, 22, 25, 27, 28, 30, 32]. Five studies [15, 18, 27, 28, 30] diagnosed dementia according to the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10) criteria [33], one study [32] used the Diagnostic and Statistical Manual of Mental Disorders,

Table 2. Overview of aims, control belief constructs, and study findings

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Burgener and Twigg [19]	191	To examine associations between caregiver factors and Quality of Life (QoL) outcomes in care recipients with dementia; descriptive longitudinal study	Well-being dimension of QoL (defined as depression and psychological well-being). Behavioral competence dimension of QoL (defined as physical impairment, functional ability of daily life, productive behaviors, and personal control)	Personal control measured 3 times with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with a higher score indicating more personal control. Cronbach's α was 0.77. Participants with dementia mean baseline score: 21.52 (4.7)	From baseline to 18 months, care recipients significantly declined in mental status, productive behaviors, and functional ability, while depression scores improved. If controlling for 12-month mental ability, quality of relationship, and activity participation predicted psychological well-being at 18 months. Depression was predicted by activity participation, and functional ability was predicted by activity participation and caregiver role stress. Quality of relationship predicted productive behaviors, and caregiver role stress combined with total social contacts predicted care recipient social behaviors. Personal control showed a significant increase from baseline to 18 months, and at 18 months was correlated to the personal distress subscale on caregiver role stress. However, personal control was not predicted by any of the studied variables
Burgener and Berger [21]	40	To examine the psychometric properties of 2 stigma measures, Stigma Impact Scale (SIS) and Stigma Experience Scale, and to determine differences in perceived stigma in persons with Alzheimer's Disease (AD) and Parkinson's Disease (PD); cross-sectional comparison study	Perceived stigma, cognitive function, disease severity, self-esteem, depression, and personal control	Personal control measured once with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with higher score indicating more personal control. Cronbach's α was 0.70. Participants with dementia mean baseline score: 23.5 (5.9)	The SIS was found to have better reliability and validity for both the AD and PD groups. Cognitive function was related to stigma for both groups, but self-esteem, depression, and personal control were only related to stigma in persons with PD. However, personal control was related to the social rejection subscale (1 of 4 subscales) of the SIS in both groups. No difference between AD and PD was found on total SIS scores, but AD participants scored higher on the internalized shame subscale. Personal control was lower in the AD group, but no difference between the groups was found on measures of self-esteem or depression
Burgener et al. [26]	97	To examine if QoL varies in the early dementia disease stages and to examine associations between perceived stigma and quality of life in persons with dementia; descriptive longitudinal study	QoL (defined as depression, anxiety, behavioral symptoms, personal control, physical health, self-esteem, social support, and activity participation)	Personal control measured 4 times with the Mastery Scale [44]: 7 items are rated on a 5-point scale, ranging from 1 (not at all true) to 5 (exactly true). Total score ranges from 7 to 35, with higher score indicating more personal control. Cronbach's α was 0.70 at baseline and 0.77 at 12 months. Participants with dementia mean baseline score: 25.5 (4.8)	Over the 18-month study, anxiety and social support and activity participation significantly decreased, while behavioral symptoms significantly increased. No changes were found on depression, personal control, self-esteem, or physical health scores. Stigma was examined at the subscale level (social isolation, internalized shame, and social isolation). Social rejection was associated with anxiety, behavioral symptoms, health, and activity participation. Internalized shame was associated with personal control, health, self-esteem, social support understanding and assistance, and activity participation. Social isolation was associated with depression, anxiety, personal control, health, self-esteem, social support understanding, and activity participation

Table 2 (continued)

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Clare et al. [18]	475	To determine whether individual goal-oriented cognitive rehabilitation (CR), compared to treatment as usual (TAU), improves everyday functioning for people with mild to moderate dementia; randomized controlled trial	Primary outcome was self-reported goal attainment at 3 months. Secondary outcomes were informant-reported goal attainment, QoL, mood, self-efficacy, and cognition, as well as partner stress and QoL	Self-efficacy measured 3 times with the General Self-Efficacy Scale (GSES) [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 30.94 (5.09)	Compared to TAU, self-reported goal attainment increased significantly in the group receiving CR, measured at both 3 and 9 months. No significant differences were found on secondary outcomes at either measuring point, including self-efficacy
Clare et al. [30]	2,748	To explore the extent to which people with dementia experience discontinuity of their subjective experience of themselves and factors associated with this experience; cross-sectional study (the IDEAL study)	Cognitive function, ability to function independently, neuropsychiatric symptoms, psychological well-being indicators (self-acceptance, self-esteem, self-efficacy, aging attitudes, optimism, loneliness, and depression), measures of living well (quality of life and life satisfaction), and caregiver stress	Self-efficacy measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean score: discontinuity group 27.04 (5.85), continuity group 29.86 (5.23)	A fifth of the participants described an experience of discontinuity. Participants in the discontinuity group were younger, with slightly more neuropsychiatric symptoms. There were no other differences between the groups on participant- or dementia-related characteristics. The discontinuity group scored lower on self-acceptance, self-esteem, self-efficacy, attitudes toward own aging, and optimism. They scored significantly higher on loneliness and depression. On living well measures, the discontinuity group scored lower on quality of life, well-being, and satisfaction with life. Caregivers in the discontinuity group reported greater distress due to neuropsychiatric symptoms, and higher levels of caregiver stress
Fankhauser et al. [25]	229	To investigate the role of motivational processes as a mediator of the relationship between social support and depression in participants with dementia, those with mild cognitive impairment (MCI), or unimpaired participants; cross-sectional comparison study	Primary outcome was depression. Explanatory variables were measures of motivational processes (a composite measure based on self-efficacy, activation regulation, motivation regulation, and decision regulation) and social support	Self-efficacy measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. Cronbach's α was 0.70. Mean baseline score not reported, as self-efficacy was examined as part of a composite measure	In the total sample, both social support and motivational processes were correlated with depression. Only motivational processes predicted depression in a regression analysis, where social support lost its significance. The association between motivational processes and depression remained significant in regression analysis controlling for age, sex, education, MMSE, cognitive impairment, and activities. In the 3 groups, the association was stronger motivational processes and depression was stronger among cognitively unimpaired participants than among dementia and MCI participants. Predictive ability was higher with less impairment

Table 2 (continued)

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Fitzsimmons and Buettner [20]	7	To report on results from an experimental college course for older adults with early-stage dementia; pilot intervention study, pretest/posttest	Depression, self-esteem, self-efficacy, and stress	Self-efficacy measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 33.17	Differences between pretest and posttests indicate a reduction in depression and perceived stress scores, an increase in self-esteem scores, and stable self-efficacy scores. Statistical analysis not performed due to small sample size
Halse et al. [27]	534	To investigate the applicability of the Locus of Control of Behavior Scale for people with dementia; psychometric evaluation, cross-sectional data	Cognitive function, depressive symptoms, and ability to function independently	Locus of control (LoC) was measured once with the Locus of Control of Behavior Scale [45]: 17 items are rated on a 6-point scale, ranging from 0 to 5. Total score ranges from zero to 85, with higher score representing more external LoC. Cronbach's α was 0.69. Participants with dementia mean baseline score: 30.8 (10.5)	Older age, less education, and poorer cognitive function decreased likelihood of scale completion. Cronbach's α remained relatively stable, despite degree of cognitive impairment, and at an acceptable level. Locus of control was associated with depressive symptoms, but not with degree of cognitive impairment
Hindle et al. [17]	55	To examine the appropriateness and feasibility of CR compared to TAU or relaxation therapy (RT) for people with dementia due to PD and Lewy body disease, and to assess usefulness of outcome measures and obtain effect sizes to guide future RCTs; pilot randomized controlled trial	Primary outcomes were rating of goal attainment and satisfaction with goal attainment. Secondary outcomes were quality of life, mood, cognition, health status, and everyday functioning. Secondary outcomes for carers were ratings of person with dementia's goal attainment, own quality of life, and stress levels	Self-efficacy was measured 3 times with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 29.45 (4.35)	Compared to TAU and RT, effect size estimates showed that CR was superior on both primary outcomes at the 2-month follow-up and partially superior at the 6-month follow-up. Furthermore, CR was superior to TAU and/or RT at 2 months on mood, self-efficacy, social domain of quality of life, and carer ratings of participants' goal attainment. At 6 months, CR was superior on delayed recall, health status, quality of life, and carer ratings of goal attainment
Lamont et al. [28]	1,547	To examine the associations between psychological resources and the ability to live well with dementia; cross-sectional study (the IDEAL study)	Primary outcome was living well (defined as quality of life, life satisfaction, and mental well-being). Explanatory variables were self-efficacy, optimism, and self-esteem	Self-efficacy was measured once with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. Cronbach's α was 0.88. Participants with dementia mean baseline score: 29.26 (5.49)	High self-efficacy (compared to low) was associated with meaningful increases on quality of life, life satisfaction, and mental well-being. Optimism and self-esteem were also associated with significant increases on each of the 3 living-well scales. In a multivariable model, the results continued to be significant, but effect sizes were reduced. Comparing standardized scores, high self-efficacy (compared to low) was still associated with increased quality of life, life satisfaction, and mental well-being, with little variation between the constructs. Optimism similarly showed little variation based on the living-well measure, but self-esteem showed greater variation

Table 2 (continued)

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Leroi et al. [31]	38	To evaluate the feasibility, acceptability, and tolerability of a new sensory intervention to support hearing and vision, and to identify the key variables for a cost-effectiveness evaluation; pilot intervention study, pretest/posttest	Persons with dementia were assessed on cognition, behavior, mental well-being, and self-efficacy. Study partners were assessed on physical and mental well-being, and caregiver burden. Both were assessed on relationship satisfaction and quality of life	Self-efficacy was measured twice with the Generalised Self-Efficacy Scale [56]: 8 items are rated on a 5-point scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Item responses are averaged, and total score ranges from 1 to 5, with higher score representing greater self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 2.85 (0.54)	Mean score increases indicated that people with dementia felt an improvement in quality of life and in hearing and vision functional abilities. Proxy rating indicated a decrease in quality of life. Measures on physical and mental functioning, neuropsychiatric symptoms, self-efficacy, and functional ability indicated only slight changes. Indications that relationship satisfaction improved according to the person with dementia but decreased according to study partners. Statistical analysis not performed due to small sample size
Logsdon et al. [24]	284	To compare a time-limited early-stage memory loss group program to wait list control; randomized controlled trial	Primary outcome was quality of life; secondary outcomes were mood, communication and interpersonal relationships, and stress; self-efficacy and memory-related behavior problems were exploratory outcomes	Self-efficacy was measured twice with the Self-Efficacy Scale [57]: 7 items are rated on a 4-point scale, ranging from strongly agree to strongly disagree. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 7.92 (1.32)	The treatment group showed significant increases on measures of participant QoL, depression, and family communication. No differences were found among caregivers in the 2 groups. For the treatment group, those whose quality of life improved reported more depressive symptoms, more stress, and more distress on several health-related quality of life subscales at baseline. They also showed greater increases in mood, family communication, and self-efficacy than non-improvers. For those who showed improvements in the waitlist group, no baseline associations were found
Quinn et al. [15]	48	To develop and evaluate a self-management intervention compared with TAU for people with early-stage dementia; pilot randomized controlled trial	Primary outcome was self-efficacy. Secondary outcomes were anxiety and depression, well-being, social functioning, problems and risks to self, health-related QoL, and a person's sense of capability-related well-being	Self-efficacy measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for the present sample were presented. Participants with dementia mean baseline score: 28.36 (4.82)	Compared to TAU, intervention participants indicated gains in self-efficacy with small effect sizes at both 3 and 6 months. The intervention participants also showed improved effect sizes for depression after 6 months and on capability-related well-being after 3 and 6 months. They had lower QoL scores at 3 months but higher scores at 6 months. At both 3 and 6 months, the intervention group had higher anxiety scores. Statistical analysis not performed due to small sample size

Table 2 (continued)

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Regan et al. [29]	661	To evaluate changes in physical function, physical activity, exercise self-efficacy, and well-being; pilot intervention study, pretest/posttest	Physical function, physical exercise self-efficacy, and mental well-being	Exercise self-efficacy was measured twice with the Self-Efficacy of Exercise Scale [58]: original scale consists of 9 items rated on a 11-point scale, ranging from 0 (not confident) to 10 (confident). Total score ranges from 0 to 100, with higher score representing greater self-efficacy. In the present study, only 4 items were used, and rated on a 3-point scale. No psychometrics for present sample were presented. Mean baseline score not reported	For participants with dementia, most physical function measures improved, and there was also an increase in frequency, duration, and intensity of physical activity after the program. Mental well-being increased, while exercise self-efficacy did not change
Roberts and Silverio [23]	74	To evaluate a 4-session education and support program for persons with early-stage dementia and their care-partners; intervention study, pretest/posttest	Participant satisfaction, improvements on AD knowledge, coping self-efficacy, and adjustment to illness, and using more support services and coping strategies were main outcomes	Coping self-efficacy was measured twice with the Illness Coping Self-efficacy Scale [59]. Original scale consists of 43 items rated on a 5-point scale, ranging from 1 to 5. In the present study, only 21 items were used, with a Cronbach's α of 0.9. Mean baseline score not reported	No significant changes were found regarding AD knowledge, coping self-efficacy, or psychosocial adjustment to the illness. Participants reported a high degree of satisfaction with the program, and at the 3-month follow-up, they had significantly increased their use of 7 out of 11 measures of coping and health behaviors
Schmitter-Edgecombe et al. [22]	9	To examine the efficacy of a group memory notebook intervention for people with very mild dementia; pilot intervention study, pretest/posttest	Cognitive performance, cognitive function, objective and subjective memory measures, and measure of independent functioning. Psychological measures of depression, anxiety and stress, and coping self-efficacy	Coping self-efficacy was measured twice with the Coping Self-Efficacy Scale [60]: 26 items are rated on a 11-point scale, ranging from 0 (cannot do at all) to 10 (certain I can do). No psychometrics for present sample were presented. Participants with dementia mean baseline score: 74.20 (19.19)	Mean increases reported by persons with dementia were found regarding use of memory strategies and all 4 measures on the daily checklist. Coaches (spouses) reported mean increases on memory ability, memory strategy use, ADL, use of techniques, use of notebook, and activity engagement. Regarding coping self-efficacy, all 5 participants reported feeling more confident that they could get support from family or friends, with mean score increases from pre- to posttreatment. No changes were seen in the use of problem-focused coping or stopping unpleasant thoughts nor on mental health

Table 2 (continued)

Authors	N	Aim and study design	Outcome and dependent measures	Control belief construct and questionnaire details	Study findings
Stockwell-Smith et al. [16]	166	To evaluate the effect of a targeted community-based psychosocial intervention on self-efficacy outcomes for care recipient/carer dyads living with early-stage dementia; intervention study, pretest/posttest with comparison group	Primary outcomes were self-efficacy, stress from the perspective of dyadic strain, and well-being (QoL and depression). Secondary outcomes were dyads' uptake and awareness of available support services	Self-efficacy was measured 3 times with the Self-Efficacy Questionnaire [61]; 10 items are rated on a 10-point scale, ranging from 1 (not at all certain) to 10 (very certain). The scale was developed for caregivers, but minor changes in wording were done to support completion by people with dementia. No psychometrics for present sample were presented. Participants with dementia mean baseline scores: symptom management 37.38 (9.44); support service 31.58 (7.26)	No significant between-group differences in either symptom management self-efficacy or support service self-efficacy. At baseline, the comparison group had higher use of education/training/support groups, with 40% compared to 16% stating they had access to such services. At T1, this had changed to 61% in the intervention group versus 30% in control, but at T2 there was no longer a difference between the groups. Finally, the intervention group's use of social support services for families dealing with memory loss was higher at T2, with 41 versus 13%. No difference was found regarding remaining service types (such as home help/social support services)
Werheid et al. [32]	13	To report on the cultural adaptation and translation of the English Cognitive Stimulation Therapy (CST) manual into German Pilot study; pretest/posttest	Cognitive function, quality of life, depressive symptoms, and self-efficacy	Self-efficacy was measured twice with the GSES [43]: 10 items are rated on a 4-point scale, ranging from 1 (not at all true) to 4 (exactly true). Total score ranges from 10 to 40, with higher score representing more self-efficacy. No psychometrics for present sample were presented. Participants with dementia mean baseline score: 27.23 (6.08)	The German version of the CST manual appears applicable. Measures of effect sizes showed participants had an increase in cognitive function on 1 of 2 scales, and an increase in self-efficacy. No changes were found on quality of life or depressive symptoms. Eight participants additionally completed a maintenance program, and results indicated no changes 6 months later

GSES, General Self-Efficacy Scale; SIS, Stigma Impact Scale; AD, Alzheimer's disease; PD, Parkinson's disease; CR, cognitive rehabilitation; TAU, treatment as usual; RT, relaxation therapy; CST, Cognitive Stimulation Therapy.

Table 3. Demographics of participants with dementia

Authors and country	Participants with dementia (other)	Age mean (SD), range	% Male	Education	Married	Degree of impairment mean (SD), range	Dementia subtype, %
Burgener and Twigg [19], USA	96 (95 caregivers)	77.3 (7.8), 55–96	43	13.4 yr (SD 3.3)	–	MMSE 21.5 (SD 4.7), 10–29	AD, VD, or mixed
Burgener and Berger [21], USA	26 (14 with PD)	77.2 (6.5)	62	12.2 yr (SD 3.5)	–	MMSE 21.8 (5.6) CDR 0.5–2.0	AD or mixed
Burgener et al. [26], USA	50 (47 caregivers)	78.3 (8.3)	–	13.3 yr (SD 4.0)	–	CDR 0.86	AD, VD, or mixed
Clare et al. [18], England and Wales	475	78.6 (7.1), 53–95	52.3	12.6 yr (SD 3.4)	70%	MMSE 23.8 (SD 3.0), 18–30	AD: 59.9 VD: 15.6 Mixed 24.5
Clare et al. [30], UK	1,465 (1,283 caregivers)	76.2 (8.5) ^a	56.4 ^a	University: 20.6% ^a	–	ACE-III: 69.6 (13.1) ^a	AD: 55.5 VD: 10.9 Mixed: 21.2 Other: 12.4
Fankhauser et al. [25], Switzerland	47 (64 with MCI, 118 controls)	78.0 (7.5)	34.0	11.7 yr (SD 3.0)	–	MMSE 22.9 (SD 3.0)	AD: 20.5
Fitzsimmons and Buettner [20], USA	7	77.9 70.7–85.5	29	–	–	MMSE 21.7	–
Halse et al. [27], Norway	534	78.4 (8.1)	41.8	>10 yr: 49.8	54	MMSE-NR 19.8 (5.6)	AD: 81.1 VD: 8.1 Mixed, LDB, PDD, FLD, or other: 10.9
Hindle et al. [17], Wales	29	76.3 (6.42) 61–85	–	10.97 yr (SD 1.55)	–	ACE-III: 71.3 (7.5) 52–81	PDD or LBD
Lamont et al. [28], England, Scotland, and Wales	1,547	76.4 (8.6)	56.4	–	–	ACE-III 69.3 (SD 13.2)	AD: 55.5 VD: 11.1 Mixed: 21.1 Other: 12.4
Leroi et al. [31], France, England, and Cyprus	19 (19 caregivers)	76 63–88	63	–	–	MOCA 17.3 (3.7) 12–23	AD: 47.3 VD: 47.3 Mixed: 5.3
Logsdon et al. [24], USA	142 (142 caregivers)	74.9 ^a	50.7 ^a	College: 47.2% ^a	72% ^a	MMSE 23.4 (4.4), ^a CDR between 0 and 1	–
Quinn et al. [15], Wales	24 (24 caregivers)	75.6 (8.4), ^a 52–88	75.0	College/university: 62.5%	83%	MMSE 23.6 (SD 2.1), ^a 20–29	AD, VD, or mixed
Regan et al. [29], Canada	343 (318 caregivers)	77.3 (7.8)	60.9	–	–	–	–
Roberts and Silverio [23], USA	37 (37 caregivers)	74.4 (7.2), 55–89	73	College: 75%	81%	23.8 (3.9)	AD: 89% Other: 11%
Schmitter-Edgcombe et al. [22], USA	5 (4 caregivers)	76.0 (9.1), 63–85	20	18 yr (SD 1.41)	≥80%	RBANS 80.4 (SD 9.6)	–
Stockwell-Smith et al. [16], Australia	88 (88 caregivers)	77.8 (7.1) ^a	57.0	≤Grade 10: 46.0% ≥Grade 11: 54.5%	68%	CDR 0.5–1 (as inclusion criteria)	–

Table 3 (continued)

Authors and country	Participants with dementia (other)	Age mean (SD), range	% Male	Education	Married	Degree of impairment mean (SD), range	Dementia subtype, %
Werheid et al. [32], Germany	13	78.8 (12.7)	46.2	-	-	ADAS-COG: 22.0 (8.02) MMSE: 21.9 (5.09)	-

MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination; CDR, Clinical Dementia Rating; ACE-III, Addenbrooke's Cognitive Examination-III; ADAD-COG, Alzheimer's Disease Assessment Scale; MCI, mild cognitive disorder; AD, Alzheimer's disease; VD, vascular dementia; Mixed, combination of AD and VD; PD, Parkinson's disease; PDD, Parkinson's disease dementia; LBD, dementia with Lewy body; FTD, frontal lobe dementia; MOCA, Montreal Cognitive Assessment. ^a Mean originally listed according to treatment groups, but combined for this review.

4th edition (DSM-IV) criteria [34], and 2 studies [16, 22] based the dementia diagnosis on the Clinical Dementia Rating Scale (CDR) [35, 41]. Two studies based the dementia diagnosis on consensus criteria. One [25] used the criteria established by the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association [36], and the other study used the criteria established by the Movement Disorder Society [37, 38] and by the Dementia with Lewy Bodies consortium [39].

Where reported, the percentage of participants diagnosed as having Alzheimer's disease (AD) ranged from 47 to 89% [18, 23, 25, 27, 28, 30, 31]. See Table 3 for overview of prevalence of diagnoses in individual studies. If specific dementia diagnoses were among the inclusion criteria, AD, vascular dementia (VD), or mixed AD/VD were the most commonly used diagnoses [15, 18, 19, 21, 25, 26, 28, 31]. One study only included participants with dementia due to Parkinson's disease (PD) or Lewy body disease [17]. The remaining studies either included all types of dementia [23, 27, 30] or did not specify the etiological dementia diagnosis [16, 20, 22, 24, 29, 32].

Dementia Severity

Degree of dementia severity was an inclusion criterion in 11 studies, all of which recruited participants with mild to moderate dementia severity [15, 16, 18, 21–23, 25, 28, 30–32]. A definition of mild to moderate severity was presented in 9 studies, using 8 different types of criteria. Mini-Mental State Examination (MMSE) score [40] was used in 4 studies, and mild to moderate dementia was defined as either ≥ 15 [28, 30] or ≥ 18 [18], or ≥ 20 [15]. The CDR [35, 41] was used in 3 studies, indicating either very mild dementia with a score of 0.5 [22], mild dementia with a score of 0.5–1.0 [16], or mild to middle stage dementia with a score of 0.5–2.0 [21]. One study used a score of ≥ 12 on the Montreal Cognitive Assessment (MOCA) scale [42] to indicate mild to moderate dementia [31], and the final study used the DSM-IV to define mild to moderate dementia [32]. A further 3 studies also had cognitive assessment requirements as part of their inclusion criteria, but without indicating their purpose [17, 24, 26].

Constructs of Control Beliefs

Although many control constructs are described in the literature [5], self-efficacy [13] was most frequently applied in the included studies of this review. In all, 7 different scales measuring self-efficacy were used in 14 studies. Eleven studies measured self-efficacy at 2 or more time

points [15–18, 20, 22–24, 29, 31, 32]. The General Self-Efficacy Scale (GSES) [43] was used in 8 studies and the remaining 6 self-efficacy scales [56–61] in one study each (see Table 2). The Mastery scale developed by Pearlin and Schooler [44] was used in 3 studies to examine personal control [19, 21, 26]. One study examined locus of control using the Locus of Control of Behavior scale developed by Craig et al. [45].

As seen in Table 2, internal consistency/scale reliability (Cronbach's α) of the control instruments was reported in 6 articles [19, 21, 23, 26–28]. One study's primary aim was to assess the applicability of the control belief scale for use among persons with dementia [27], while no other studies reported or did any validation of the control belief scales for the included study population. However, no studies reported methodological difficulties with the use of the control belief instruments.

Findings Regarding Control Beliefs

Five studies examined control beliefs using cross-sectional data. Clare et al. [30] examined the experience of discontinuity in the subjective experience of one self and found that this was associated with lower scores on self-efficacy. Fankhauser et al. [25] found that motivational processes (self-efficacy and activity, motivation, and decision regulation) were associated with depression and furthermore that motivational processes, not degree of social support, predicted depression in a regression analysis. In the study by Lamont et al. [28], high self-efficacy was found to be associated with increases on 3 different living-well scales. However, the effect sizes were reduced when accounting for shared variance with optimism and self-esteem, considered by the authors to be 2 related concepts. Burgener and Berger [21] examined differences in experiences of stigma among participants with AD and PD. They found that personal control was lower among those with AD and only associated with stigma among those with dementia due to PD. Finally, Halse et al. [27] found more external locus of control to be associated with more depressive symptoms, but no association between locus of control and cognitive function.

Two descriptive longitudinal studies examined personal control as one of several quality of life variables for participants with dementia. Burgener and Twigg [19] found improvements in personal control over an 18-month period; however, the main hypothesis that such a change could be predicted by caregiver factors was not supported. Burgener et al. [26] examined effects of perceived stigma on quality of life variables and found that personal control was associated with both the social

isolation and internalized shame stigma subscales. This was more prominent among participants living in urban areas in the USA and those of African American descent.

The 11 intervention studies reported overall positive effects of the various interventions; however, only 5 found these effects to be potentially associated with changes in control beliefs. Examining the efficacy of an early stage memory loss support group, Logsdon et al. [24] found that the intervention was associated with increased quality of life and that this increase was associated with improved self-efficacy. Quinn et al. [15] found that self-efficacy effect sizes increased in the group receiving a self-management intervention compared to that in a group receiving treatment as usual. This increase persisted 6 months post-intervention, along with improved effect size increases in depression and well-being scores. Statistical analysis was not performed due to small sample size. Hindle et al. [17] found that goal-oriented cognitive rehabilitation was superior regarding self-efficacy at 2 months to both relaxation therapy and treatment as usual, but the effect was not sustained at the 6-month follow-up. Two small pilot studies also reported on improved self-efficacy after interventions [22, 32]. In their process of translating and validating a cognitive stimulation therapy manual using 13 participants with dementia, Werheid et al. [32] found that self-efficacy increased from pretest to posttest. Schmitter-Edgecombe et al. [22] found that their 5 participants with dementia showed an increased self-efficacy regarding beliefs about obtaining support from family or friends, one of 3 subscales on the Coping Self-Efficacy Scale.

Finally, 6 studies reported effective interventions, but found no changes in control beliefs. Clare et al. [18] found that goal-oriented cognitive rehabilitation was effective with regard to improved everyday functioning; however, self-efficacy did not change. In a large study evaluating effect of an exercise intervention of physical function, activity, well-being, and exercise self-efficacy, Regan et al. [29] reported increases on all outcomes except self-efficacy. Stockwell-Smith et al. [16] examined effectiveness of a psychosocial intervention for care recipients and carer dyads using both quantitative and qualitative methods. Statistical differences on self-efficacy were not found; however, qualitative reports postintervention indicated increased self-efficacy regarding identifying and accessing community support. Roberts and Silverio [23] examined a 4-session educational and support program. Although the 37 participants with dementia increased their use of several measured coping and health behaviors, no statistical changes were found regarding coping self-effi-

cacy or psychosocial adjustment to the illness. In a small study including 19 participants with dementia, Leroi et al. [31] examined effectiveness of a sensory intervention to improve quality of life for participants with hearing and/or vision impairment. Mean increases in quality of life were reported as clinically significant, but only slight changes were found regarding self-efficacy. Finally, Fitzsimmons and Buettner [20] concluded that their group interventions target health promotion as a success, but mean self-efficacy scores remained stable.

Discussion

To the best of our knowledge, this is the first systematic review conducted of scientific studies investigating constructs of control beliefs among people with dementia. We found 18 studies that met our inclusion criteria, examining a total of 3 different constructs using 9 different control belief scales. The studies had a wide variety of research aims and designs, with good methodological quality. However, 7 studies were pilots, and as many as 10 studies included <50 participants with dementia. Low-powered studies reduce the possibility of detecting effects, increase possibility of false positives, or may inflate effects sizes of valid effects.

Most of the included studies examined control beliefs in relation to an intervention. Knowledge about perceived control is valuable when designing and implementing psychosocial interventions to support and enhance coping with a dementia disorder. Regardless of the idiosyncratic ways dementia can evolve, there is inevitably a fall in functioning in daily activities, in social activities, and in autonomy. A common coping mechanism is withdrawal from that which has become difficult, leading to reduced social network, increased isolation, and increased feelings of helplessness. Some become overwhelmed and experience symptoms of anxiety and depression [46]. Intervention programs should preferably be offered before this happens.

The interventions reported in this review were diverse, aiming to examine feasibility of cognitive rehabilitation, effectiveness of physical exercise, or effectiveness of addressing hearing and vision difficulties [17, 18, 22, 29, 31]. Other interventions aimed to improve a variety of quality of life variables [15, 20, 23, 24, 32] or to increase the use of support services [16]. Two studies had control beliefs as a primary outcome [15, 16]. Both considered their intervention effective, and one found indication of increased self-efficacy [15].

Five studies had follow-up measures after 6 or more months from baseline. One study reported an increase in personal control over an 18-month period [19], while the other 4 with a timespan of 6 months or more did not find control belief changes [16–18, 26]. However, most studies had a shorter time frame with measures done at baseline and again typically after 2 or 3 months. Dementia progresses differently for all individuals, but in the mild stages of the disease, it can be assumed that the changes are slow and minor. More longitudinal data on the associations between cognitive status and control beliefs are thus needed to examine whether cognitive decline affects a person's perception of control. The included studies could not answer this question because of too short follow-up time and being low-powered.

By observing baseline data, it appears that level of perceived control among people with dementia is comparable to other populations without dementia. The GSES was used in 7 studies, with mean baseline scores ranging from 27.2 to 33.2 [15, 17, 18, 20, 28, 30, 32]. Though not comparable in age, a similar GSES mean of 29.46 (SD 5.33) was reported in a large study with 19,120 participants from 25 countries [47]. Furthermore, the descriptive longitudinal studies measuring personal control with the Mastery scale found mean baseline scores ranging from 23.5 to 25.5. Similar means have been reported among middle-aged adults [48] and older adults without dementia [49]. Although caution is needed in interpreting the results of the included studies due to small sample sizes, it indicates that self-efficacy and personal mastery levels among people with dementia resonate other populations. This is encouraging, from both methodological and coping perspectives.

Studies reporting cross-sectional results found several important associations of control beliefs in people with dementia that are useful for our understanding of coping with the diseases. Two studies examining self-efficacy found that a higher level was associated with less depression and better quality of life [25, 28], resonating findings among older people with depression [8, 50]. Compared to people with PD, people with AD reported less personal control and scored higher on the internalized shame subscale of a stigma measure [19]. Finally, low self-efficacy was associated with experiencing a discontinuity in their sense of self because of the dementia disease [30]. This feeling of discontinuity was associated with several negative measures, such as higher scores on loneliness and depression and lower scores on quality of life.

The results found in this review support conclusions made by others, for example, that persons with demen-

tia are prone to thoughts of helplessness, loss of identity, and embarrassment, particularly in the mild stages of the disease process [46, 51]. People with dementia may also be prone to lowered expectations and prejudice by those in their surroundings, and so-called *dementia-ism* can be a source of stigma and negative self-stereotypes [52]. Addressing low control expectations has been shown to positively affect memory training among older adults with cognitive deficits [53, 54]. Health-care personnel and informal caregivers assisting people with dementia should focus on control beliefs to enhance coping. Supporting people with dementia to reach own goals by focusing on increasing their perception of control could lead to empowering effects and may thereby reduce some of the negative psychological effects of the disease.

Apart from the study by Halse et al. [27] that validated the Locus of Control of Behavior Scale for people with dementia, none of the studies reported having validated the control belief questionnaire for the current population. Still, the studies did not report difficulties with the use of such questionnaires. Depending on the degree of cognitive deficit, people with dementia may be expected to struggle with questions that require judgments on a Likert-type scale, which is commonly used in such questionnaires. One could speculate that they would answer arbitrarily if they did not understand the questions or how to respond. This should be detectable in an internal reliability analysis, and 7 studies reported a Cronbach's alpha score ranging from 0.69 to 0.90. This indicates that reliable data regarding control beliefs using quantitative measures can be acquired in this manner, which is supported by the study of Halse et al. [27]. Therefore, we suggest that persons with dementia should be included in this type of research as their voices are important and informative.

Notably, the 18 studies tended to include participants with mild to moderate dementia, and most of those included had either AD, VD, or a mix of these diseases. Although there is an overall lack of knowledge regarding control beliefs among persons with dementia, studies should also include participants in the severe stages of the disease and with other dementia diagnoses. Furthermore, studies focusing specifically on subgroups with comorbidities such as depression or anxiety would likely give further knowledge on who and how a person with dementia could benefit from a focus on control beliefs to increase coping effectiveness.

This review applied a broad search strategy regarding terms to cover both dementia and control beliefs, and

thereby, it should capture most of what has been published in English and in peer-reviewed journals. Furthermore, we applied a strict definition of dementia, meaning that studies mixing our target group with people with mild cognitive impairment were excluded. This was done in order to promote the generalizability of our findings, a necessity also advocated by others [55]. However, particularly due to the exclusion of non-English articles, there may exist additional research on the topic that is missing in this review.

Conclusion and Future Directions

Understanding how experiences of control influences coping can make it easier for informal caregivers and health-care personnel to give effective support to the person with dementia, allowing them to live independently longer and thereby prevent premature burden on society. This systematic review revealed that too few and small studies exist to conclude on the relations between perceived control and dementia; thus, there is a need for more robust studies. However, our findings support that quantitative research on control beliefs among people with dementia is feasible, and people with dementia are recommended to be included in this type of research. The rising interest in this field of knowledge is encouraging, as it may enlighten best practice and help in the development of effective interventions so that people with dementia can cope and live well with their disease.

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Statement of Ethics

The study is exempt from Ethical Committee approval as it is a review based on already published research data.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

I.H., K.E., G.H.B., G.S., and M.L.B. contributed to the design and/or analysis and/or interpretation of data and have contributed in the drafting, revising, and final version of the manuscript. They all agree to be held accountable for the content of the manuscript and have signed an Author Submission Statement declaring this.

Appendix 1

Search words for dementia in different databases

Database	Dementia terms
EMBASE	Dementia/OR Alzheimer disease/OR parkinsonism/OR (lewy adj1 bod*).ab,kw,ti. OR (Parkinson* adj1 dementia).ab,kw,ti. OR (dementia* or alzheimer*).ab,kw,ti. OR (frontotemp* adj1 dementia).ab,kw,ti. OR (vascul* adj1 dementia).ab,kw,ti.
MEDLINE	Dementia/or alzheimer disease/or dementia, vascular/or frontotemporal lobar degeneration/or lewy body disease/OR (dementia* or alzheimer* or (lewy adj1 bod*) or (parkinson* adj1 dementia*)).ab,kf,kw,ti. OR parkinsonism.mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
CINAHL	TI dement* OR AB dement* OR SU dement* OR TI alzheimer* OR AB alzheimer* OR SU alzheimer* OR (MH "Lewy Body Disease") OR TI parkinson* N1 dement* OR AB parkinson* N1 dement* OR SU parkinson* N1 dement* OR (MH "Dementia+") OR (MH "Alzheimer's Disease")
PSYCHINFO	Dementia/or dementia with lewy bodies/or presenile dementia/or semantic dementia/or senile dementia/or vascular dementia/OR alzheimer's disease/OR "alzheimer*".ab,mh,sh,ti. OR "dement*".ab,mh,sh,ti. OR (lewy adj1 bod*).ab,mh,sh,ti. OR (parkinson* adj1 dement*).ab,mh,sh,ti.
AGELINE	DE "Dementia" OR DE "Alzheimers Disease" OR DE "Early Onset Dementia" OR DE "Frontotemporal Dementia" OR DE "Lewy Body Dementia" OR DE "Vascular Dementia" OR DE "Vascular Dementia" OR DE "Lewy Body Dementia" OR DE "Frontotemporal Dementia" OR DE "Early Onset Dementia" OR DE "Alzheimers Disease" OR AB (dementi* or alzheimer*) OR TI (dementi* or alzheimer*) OR SU (dementi* or alzheimer*) OR TI parkinson* N1 dementi* OR AB parkinson* N1 dementi* OR SU parkinson* N1 dementi* OR AB lewy N1 bod* OR TI lewy N1 bod* OR SU lewy N1 bod*
COCHRANE	MeSH descriptor: [Dementia] explode OR MeSH descriptor: [Alzheimer Disease] explode OR (dementi* OR alzheimer* OR lewy OR parkinsonism):ti,ab,kw

Appendix 2

Search words for control and coping in different databases

Database	Coping terms
EMBASE	Coping behavior/OR (coping adj1 (strateg* or style* or mechanism* or behavio* or way*)) .ab,ti,kw. OR "locus of control assessment"/OR internal-external control scale/OR "multidimensional health locus of control scale"/OR "locus of control"/OR "locus of control".ab,kw,ti. OR control/OR *self concept/OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti. OR "sense of coherence scale"/OR "sense of coherence"/OR "sense of coherence".ab,kw,ti. OR learned helplessness.ab,kw,ti. OR learned helplessness/OR personal causation.ab,kw,ti. OR situation appraisal.ab,kw,ti. OR perceived competence.ab,kw,ti. OR efficacy expectancies.ab,kw,ti. OR "agency belief*".ab,kw,ti. OR ways of coping.ab,kw,ti. OR mastery.ab,kw,ti.
MEDLINE	(Coping adj1 (strateg* or style* or mechanism* or behavio* or way*)) .ab,ti,kw,kf. OR Internal-External Control/OR "locus of control".ab,kw,ti,kf. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,kw,ti. OR self-efficacy.ab,kw,ti,kf. OR "sense of coherence".ab,kw,ti,kf. OR learned helplessness.ab,kw,ti,kf. OR personal causation.ab,kw,ti,kf. OR situation appraisal.ab,kw,ti,kf. OR perceived competence.ab,kw,ti,kf. OR efficacy expectancies.ab,kw,ti,kf. OR "agency belief*".ab,kw,ti,kf. OR ways of coping.ab,kw,ti,kf. OR mastery.ab,kw,ti,kf. OR Internal-External Control/OR Helplessness, Learned/OR Self Efficacy/OR "Sense of Coherence"/OR Adaptation, Psychological/
CINAHL	(MH "Coping+") OR TI ((coping w1 (behavio** OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR (MH "Locus of Control") OR (MH "Self Regulation") OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR (MH "Helplessness, Learned") OR sense of coherence OR "mastery" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy) OR TI locus of control OR AB locus of control OR SU locus of control
PSYCHINFO	(Coping adj1 (strateg* or style* or mechanism* or behavio* or way*)) .ab,ti,sh. OR "internal external locus of control"/OR "locus of control".ab,ti,sh. OR (control adj1 (personal or subjectiv* or belief* or perceived or orientation or sense or expectancy)).ab,sh,ti. OR self-efficacy.ab,sh,ti. OR "sense of coherence".ab,ti,sh. OR learned helplessness.ab,ti,sh. OR personal causation.ab,sh,ti. OR situation appraisal.ab,sh,ti. OR perceived competence.ab,ti,sh. OR efficacy expectancies.ab,ti,sh. OR "agency belief*".ab,ti,sh. OR ways of coping.ab,ti,sh. OR mastery.ab,ti,sh. AND Helplessness, Learned/OR Self Efficacy/OR "sense of coherence"/OR coping behavior/OR *self-control/OR helplessness/or learned helplessness/OR exp Self-Perception/
AGELINE	DE "Coping Behavior" OR TI ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR AB ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR SU ((coping w1 (behavio* OR style* OR strateg* OR mechanism* or way*))) OR TI ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR AB ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR SU ((control N1 (orientation OR sense OR expectancy OR belief* OR personal OR perceived or expectancy))) OR DE "Learned Helplessness" or DE "Locus of Control" or DE "Self Efficacy" OR TI (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR AB (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR SU (efficacy expectancie* or agency belief* or situation appraisal* or perceived competence* or mastery or self-efficacy or sense of coherence) OR TI locus of control OR AB locus of control OR SU locus of control
COCHRANE	MeSH descriptor: [Adaptation, Psychological] explode OR MeSH descriptor: [Self Concept] explode (coping):ti,ab,kw OR (locus of control):ti,ab,kw OR ("control orientation" or "sense of control" or "control expectancy" or "control belief*" or "personal control" or "perceived control" or "perception of control" or "self-efficacy" or "sense of coherence" or "personal causation" or "learned helplessness" or "situation appraisal" or "perceived competence" or "efficacy expectanci*" or "agency belief*" or "way* of coping" or mastery):ti,ab,kw

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